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PRINCIPAL INVESTIGATOR: Jack A. Clark, Ph.D.

CONTRACTING ORGANIZATION: Boston University  
Boston, MA 02118

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**6. AUTHOR(S)**

Jack A. Clark, Ph.D.

**7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES)**Boston University  
Boston, MA 02118

E-Mail: jaclark@bu.edu

**8. PERFORMING ORGANIZATION  
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To examine men's perceptions of life transitions associated with prostate cancer through an analysis of their narratives, obtained in in-depth, qualitative interviews; compare men's narratives of perceived transitions with respect to quality of life outcome states, i.e., good vs. poor prostate cancer-related quality of life. Phase 1: interview participants in our quality of life survey of previously treated patients, stratified by quality of life. Phase 2: interview members of our prospective cohort who have completed 36-month follow-up, stratified by quality of life states and observed changes in urinary, bowel, and sexual function. Phase 3: prospectively interview patients with new diagnoses of early prostate cancer prior to treatment and 12 months later. Comparative analyses, with comparisons between strata and the three cohorts, will characterize the structure and content of patients' narratives of prostate cancer, including specific changes in identity and interpersonal relationships, that are linked to quality of life outcomes. Interviews conducted so far include: Phase 1, 24; Phase 2, 25; Phase 3, 38. Survey instrument to identify quality of life strata in prospective cohort was completed by 235 of 269 eligible patients (87%). Analysis of completed interviews is in progress; no reportable findings as yet.

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## INTRODUCTION

An estimated 190,000 American men, mostly aged 50 and older, will be told by their doctors that they have early prostate cancer this year. For many, if not all, this news will precipitate a crisis. They will be confronted with an ominous diagnosis and asked to make choices between a growing number of therapeutic alternatives (radical prostatectomy, external beam radiotherapy, brachytherapy, cryosurgery, observation/expectant management) in a context of uncertainty. While none of the active treatment alternatives has been shown to offer an efficacy advantage over observation, each is associated with long-term urinary, bowel, and sexual complications, which may have substantial effects on quality of life. Most of these men will survive for many years, some living with problematic treatment-related physical changes, psychosocial changes, and the possibility that treatment did not eliminate prostate cancer as a serious threat. The growing appreciation of the salience and magnitude of these effects, for both individual patients and an aging population, has resulted in advances in our knowledge of quality of life outcomes, informed by improved methods for measuring prostate cancer-related quality of life. Yet, our understanding of how men respond cognitively and emotionally to the diagnosis of prostate cancer and its treatment remains limited. In particular, we lack information about how men perceive the changes they go through, from their pre-treatment state to their health and quality of life state after treatment.

However, advances in social and behavioral science methods for studying how people perceive and make sense of their own lives through personal narratives offer a productive approach for research on the changes in quality of life that may be occasioned by the diagnosis and treatment for early prostate cancer. Narratives have clearly identifiable grammatical structures. They can be rigorously analyzed as meaningful social objects. Moreover, there is growing interest in patients' narratives of their illnesses within the medical community. Clinicians and researchers are regaining an appreciation for patients' stories, an interest as ancient as Hippocrates, since the stories individuals tell about themselves when ill reveal the ways in which they understand their illnesses and the impacts of illness on their lives.

Our study will extend a productive line of research on men's perceptions of the physical and psychosocial impacts of prostate cancer. We have developed questionnaires, research designs, and substantial databases for studying men's perceptions of the physical complications of treatment for early prostate cancer and the psychosocial impacts of these complications, as well as the emotional, symbolic effect of a cancer diagnosis. Much of this work has been strongly informed by what men say in open-ended discussions of their experiences, such as focus groups. Often, when asked to describe in their own words the impact of prostate cancer, men will begin by saying something like, "Well, it's a long story."

In this study, we will build on our previous research, particularly our well developed quantitative databases, to collect and analyze systematically men's narratives of prostate cancer, and examine their relationship with physical and psychosocial outcomes of care. We will proceed in three phases. First, we will identify men who have completed psychosocial questionnaires in our current survey of quality of life outcomes, and who fall into one of several contrasting outcome groups, that is, good or poor quality of life. We will interview these men, all of whom were diagnosed 12 to 48 months previously, elicit their narratives, and compare the stories associated with either good or poor quality of life. Second, we will verify the findings of

the first phase by replicating the analysis among men who have participated in a long-term follow-up study of physical complications of treatment. Thus, we will also examine the association between men's stories and carefully observed physical changes in urinary, bowel, and sexual function. Third, we will directly examine developing stories of the impact of prostate cancer by prospectively interviewing a small group of newly diagnosed men at two points in their prostate cancer "careers," shortly after diagnosis and 12 months later.

## **BODY**

Task 1: Characterize men's retrospective perceptions of life transitions associated with early prostate cancer in a sample of previously treated patients, Months 1-12.

- a. Identify subsample of 40 respondents to prostate cancer quality of life survey, defined by quality of life outcome status
- b. Conduct in-depth interviews with subsample of respondents.
- c. Analyze men's narratives of their lives with early prostate cancer.

A total of 24 patients who participated in the previous (1999) quality of life survey were successfully interviewed in accomplishing Task 1. Others who we attempted to contact and interview were either lost to follow-up (no longer at last known address; unable to locate) or declined our invitation to participate in an interview. Combined with 35 subjects interviewed from that survey panel prior to the initiation of this project, we have produced a very large database of 59 in-depth, qualitative interviews with patients previously treated for early prostate cancer.

All completed interviews have been transcribed and entered into the qualitative database. Analyses are underway. We are constructing a data dictionary that represents the major topics pertaining to the experiences of diagnosis, treatment decision making, and quality of life outcomes of treatment for early prostate cancer.

Task 2: Characterize men's retrospective perceptions of life transitions associated with early prostate cancer in a cohort of patients in which urinary, bowel, and sexual function have been monitored from pre-treatment baseline to 36 months post-treatment, Months 13-24

- a. Administer survey, using patient-centered quality of life measures, to members of prospective cohort.
- b. Identify subsample of 40 respondents to quality of life survey, defined by changes, from pre-treatment status, in urinary, bowel, and sexual function, and by quality of life status.
- c. Conduct in-depth interviews with subsample of respondents.
- d. Analyze men's narratives of their lives with early prostate cancer.

A survey instrument, based on the instrument developed in our previous survey of prostate cancer patients, was developed and sent to members of the cohort who had completed 36 months of follow-up in the Talcott/Clark prospective survey of urinary, bowel, and sexual function following treatment for early prostate cancer. A copy of this questionnaire is appended. Eligible patients had valid baseline and 36 month data. Interim data, collected at 3, 12, and 24 months after the initiation of treatment or indication of a choice to pursue a "watch and wait"

treatment approach, were also largely complete, but completion of interim data was not required for inclusion in Task 2. Of 338 names received from Talcott, 43 were excluded because of lack of valid baseline data; 19 were excluded because of lack of valid address; and 7 were deceased. The remaining 269 were sent questionnaires: ten actively refused and 24 declined to respond. Responses were obtained from 235 of 269: a response rate of 87.3%.

As planned, the survey data provided an opportunity to verify previous psychometric findings regarding psychosocial dimensions of prostate cancer-related quality of life. Psychometric analyses confirmed 11 previously defined quality of life scales, plus one new scale to assess the behavioral consequences of treatment-related bowel dysfunction.

Two of these scales were used to define four contrasting outcome groups for follow-up interviews: perceived cancer control and perceived quality of decision making. The former assesses confidence in cancer control and related distress about possible progression. The latter assesses perceptions of having made a well informed decision in choosing a course of treatment. Together, they represent perceptions of the overall effectiveness of cancer treatment. These two scales were relatively unrelated ( $r=.28$ ). Groups were defined according to median splits on these two dimensions, allowing classification of 225 of 235 subjects with sufficient data on the two scales.

Quality of life characteristics of the four groups are summarized in Table 1. In order to provide optimum contrast groups for the qualitative analyses of Task 2, we have sampled patients in maximally different Groups 1 (poor (-) control, poor (-) decision) and 4 (good (+) control, good (+) decision). Interviews elicit narrative accounts leading to good and poor quality of life conclusions.

We have interviewed 25 patients in completing Task 2. Additional interviews were unsuccessfully sought from 34 respondents, including 22 who could not be reached, 1 who died shortly after completing the quality of life survey, and 11 who declined to participate in an interview. While the number of participants is substantially less than the accrual goal, the 25 interviews comprise an adequate database for analysis. All four of the planned strata are represented.

	1 - control - decision	2 - control + decision	3 + control - decision	4 + control + decision	p
All values are means, unless noted as %					
Number of Subjects	66	47	48	64	
Age at Diagnosis	66	63	65	63	.035
PCS - 12	46	48	46	50	.044
MCS - 12	49	53	53	54	.005
MHI-5	74	79	81	83	.002
Vitality	56	61	59	68	.006
% Surgery	23	38	43	37	.001
% EBRT	65	36	39	29	
% Brachytherapy	11	22	7	29	
% Observation	2	4	11	5	
Urinary Incontinence	14	14	16	15	.901
Urinary Incontinence worse since pre-treatment	24	32	32	32	.727

**Table 1: Characterization of Four Outcome Groups**

	1	2	3	4	p
	- control	- control	+ control	+ control	
	- decision	+ decision	- decision	+ decision	
All values are means, unless noted as %					
Number of Subjects	66	47	48	64	
Urinary Obstruction/Irritation	23	18	22	19	.190
EPIC Urinary Bother	17	11	15	12	.199
Bowel Dysfunction	11	7	8	5	.024
Bowel Dysfunction worse since pre-treatment	25	22	17	13	.431
EPIC Bowel Bother	14	8	10	5	.012
Sexual Dysfunction	82	58	78	63	<.001
Sexual Dysfunction worse since pre-treatment	47	54	60	57	.518
EPIC Sexual Bother	55	43	54	42	.088
Urinary Control	90	95	92	95	.107
Bowel Control	89	91	92	96	.173
Sexual Intimacy	60	68	65	72	.093
Sexual Confidence	27	47	33	45	<.001
Masculine Self Esteem	80	87	86	89	.003
Health Worry	28	20	9	11	<.001
PSA Concern	62	75	68	65	.150
MOS Marital Function	74	86	82	84	.002
Spouse Affection	83	93	92	92	.008
% Regretful	14	4	10	0	.015
Outlook	39	47	46	48	.401
Stigma	6	2	3	2	.058
Somatic Awareness	70	65	73	73	.183
Most Recent PSA (%)					
≤ 0.1	20	38	52	44	.024
> 0.1 but ≤ 1	29	19	31	27	
> 1 but ≤ 4	23	26	8	16	
> 4	15	9	2	5	
don't know	12	9	6	8	
PSA ever rise (%)					
yes	36	34	11	19	<.001
no	48	66	85	78	
don't know	16	0	4	3	
PSA Trend (%)					
falling	19	11	13	25	<.001
staying the same	49	65	81	74	
rising	29	24	6	2	
don't know	3	0	0	0	
PSA Failure (≥ 1.0 or rose or rising) (%)	70	57	27	38	<.001
Social Support	60	84	66	83	<.001
Marital Status (%)					
married	76	89	74	91	.090
widowed	15	6	9	6	
divorced	5	4	13	3	
never married	5	0	4	0	



Task 3: Characterize men's prospective perceptions of life transitions associated with early prostate cancer in a cohort of patients observed prior to treatment and 12 months following the initiation of treatment, Months 10-27.

- a. Identify and recruit cohort of 40 patients with newly diagnosed early prostate cancer at two sites: VAMC's at Buffalo, NY and Washington, DC.
- b. Conduct baseline, in-depth interviews
- c. Conduct 12-month follow-up interviews.
- d. Analyze men's narratives of their lives with early prostate cancer.

As indicated in the 2003 annual report, the Washington, DC site was replaced by Boston Medical Center, Department of Urology. Administrative problems at Washington, DC VAMC entirely precluded efficient implementation of the project at that site. The change in protocol was approved by the Boston University Medical Center Institutional Review Board on 22 January 2003.

We have completed baseline and 12 month follow up interviews with 32 patients with newly diagnosed early prostate cancer. In addition, baseline interviews were completed with seven participants who could not be reached for follow-up interviews. One patient who was contacted and who consented to participate was subsequently dropped from the study when it was learned, during the baseline interview, that he had metastatic prostate cancer. No additional interviews will be conducted in completing Task 3. Completed interviews have been transcribed and entered into the qualitative database. Analysis is in progress.

Task 4: Complete comparative analysis of narratives elicited in three cohorts, Months 28-34

Preliminary analyses of the interviews conducted in accomplishing Tasks 1, 2, and 3 are leading to the development of a generic codebook for analyzing these accounts of living with prostate cancer. The codes are being developed through grounded theory methods, as described in the study protocol. The codes represent and organize the content of the accounts.

### **Survivor narratives – quality of life redefined and identity issues**

Analysis of men's narratives of prostate cancer has allowed us to explore personal transitions associated with diagnosis and treatment for early prostate cancer. Each man provided narrative accounts of their experiences with diagnosis, treatment and treatment sequelae, as well as accounts of their personal lives, family lives, and personal histories. In this sense, the accounts are viewed here as situated accounts men's lives with prostate cancer. That is, men portrayed themselves as survivors or victims of prostate cancer, and did so by providing rich context about their lives.

The interview thus can be considered a situated accounting of each man's life with prostate cancer. It consists of that which each man chooses to reveal to the particular interviewer in the context of a study on prostate cancer quality of life. The following are moments of the account, that is categories that capture significant aspects of the account provided by men in their interviews: 1) disease; 2) disease acts; 3) physical dysfunction; 4) social context and 5) identity.



## Disease

This category marked segments in which men talked about cancer, cancer control, and mortality as it relates to cancer. These segments are marked to explore ways in which men experience their cancer. In addition we marked discussions about other comorbid disease in order to understand the context of health and illness, both past and present, that may be related to how men view their cancer.

The interviews with the men who participated in this study of course contained many references to prostate cancer. However, in listening to what they said, we noticed that they would speak both about cancer as a general category of disease experience that would threaten their survival and peace of mind, and prostate cancer in particular as the relatively specific, problematic disease that diminished the quality of their lives. Hence, we developed a set of "Cancer" codes in order to capture the various ways in which these men talked about both the particular and the more generalized disease that had compelled their attention.

Our analysis has identified seven principal attributes of cancer that are represented in the accounts of men with prostate cancer. First is *cancer's tendency to grow, steadily and progressively*. The men would impute a history of cancer growth prior to their diagnosis. They would presume that their cancers would have grown relentlessly if they had not been treated. Second is *cancer's controllability*. Treatment could provide control, although the men varied in their estimates of the probability and of control. Some felt that the progress of their cancer was, or should have been, arrested by undergoing surgery or radiation therapy; others thought that therapy might only retard the relentless growth of the disease. Third is *cancer's visibility*. Prior to diagnosis, prostate cancer had been largely invisible, with no symptomatic or other manifestations. Some men recalled previous PSA tests as having little relevance as "cancer." However, since treatment, PSA levels acquired considerable import as vital indicators of an otherwise occult disease.

The fourth and fifth attributes of cancer concern *the personal relevance and personality of prostate cancer*. With respect to the former, prostate cancer was construed by some men as part of their person. It was personal, embodied disorder. For others, it was identified as an external object, afflicting them but not part of them. Related to this way of talking about prostate cancer, the fifth attribute had to do with the personality that some men ascribed to their cancer, and cancer in general. Cancer was characterized as having agency of its own. It had volition as either a problematic part of oneself, or as an alien antagonist.

Finally, two attributes reflected the ends of cancer. One was cancer's quality as a *typically fatal disease*. The growth ends in death. The other was the *progressive diminishment of oneself* in the face of cancer. Cancer eventually involves wasting away, with loss of function and dignity.

These seven attributes, although not explicitly mentioned by every man who was interviewed, and varying in the details of their use as descriptors, comprise the ways in which the underlying object that set the stage for men's accounts of treatment and quality of life outcomes.

The genesis of their problems in their lives since treatment was this disease that could be visible or invisible, signified by PSA values, an uncomfortable part of them or a malevolent actor *who* had entered their lives.

### Disease Acts

These segments refer to actions taking with regards to the cancer itself. They include 1) discovery, 2) decision account; 3) account of treatment. Discovery refers to the way in which the man says he found out about the cancer. This may include PSA testing, biopsies, and the actual receipt of the diagnosis. It also includes symptoms a man says he had that made him concerned. The account of the treatment includes anything about how it was to undergo treatment.

Decision account is the account provided about coming to a decision about which treatment to undergo. Decision account was subcoded to explore what kinds of things contribute to a man's decision to undergo a particular kind of treatment. Rather than focusing solely on survival or the importance of treatment side effects for each man, this analysis extends decision making. We considered:

- 1) Agency: Who makes the decision? The primary decision maker is sometimes the man himself and at other times the doctor alone. However, most men described a situation in which the man, doctor and sometimes spouse or family member made the decision together.
- 2) Mediators:
  - a. What are the different kinds and sources of information men use to make the decision? Men may rely solely on the information provided by a single physician or may consult multiple physicians from different specialties. However, some men did not only rely on physicians. Rather they drew on information provided by friends and family who had prostate cancer, information culled from the press and Internet or from books and medical journals.
  - b. What kinds of treatment complications are considered to be of importance to that individual? Some men considered the potential for urinary, sexual and bowel dysfunction as important in choosing a treatment. For some men, complications were not considered, and the sole consideration for deciding up on the treatment was how well the treatment was perceived to be able to control or cure the cancer. Others chose treatment that was most conventional – that is, they believe that this is what is usually done.
- 3) Problem: What is the nature of the problem? Some men perceive cancer to be more serious and urgent than others. Some see it as life threatening. Others see it as a medical problem to be dealt with, removed and cured. Others still see it as life altering, affecting the ways in which they see themselves and their lives.
- 4) Perceived options: Many men we spoke to did not perceive that they had any options available to them. Some simply thought that there was only one possible treatment, while others believed that due to their age or the kind of cancer, they could only have one type of treatment.

For example, one man may simply take the advice of his doctor to have surgery without consulting others, read little about the cancer, not consider the side effects or seek out other information about the cancer, perceive few options for treatment and consider the problem simple – just to remove the cancer and move on. In contrast another man may seek the advice of many, including friends and family, may make the decision with his wife and his doctor, may carefully consider the impact of potential incontinence and erectile dysfunction as well as the possibility of cure, and may seek information from multiple sources including the internet, newspapers and journal articles. This man may see the problem of cancer as being unsolvable,

ongoing and serious, and may perceive that there are many options, all with potential benefits and potential drawbacks.

These illustrate the complexity of making a decision about prostate cancer and men experience the decision making process very differently.

### **Physical Dysfunction**

**Urinary Dysfunction:** Men describe the side effects of treatment including urinary dysfunction, sexual dysfunction, bowel dysfunction and other symptoms such as fatigue and hot flashes most often associated with hormone ablation therapy. Urinary segments were subcoded to examine the impact of urinary problems on social life, the strategies men used to manage urinary incontinence, urgency and frequency and issues related to a shift in identity due to lack of control of urinary continence. Subcodes were divided into 2 major categories.

The first category reports about oneself as *embodied and a urinating being*. That is, disruption of the bodily functions that control urine discharge is experienced as dysfunctions of one's embodied self. These reports include the phenomenal experience of urination, expressions of the awareness of limitations associated with urination and urinary control, claims to a valued identity occasioned by the need to restore one's self image and/or protect it from public spoilage (stigma), expressions of emotions associated with experiences of risk, restoration, and defense, and the interpersonal transactions that take place, i.e., any relating of an event or managing urinary incontinence in relation to other social actors. Finally, it includes the practical "costs" of urinary dysfunction, referring to reports of loss of time or sleep, the nuisance of urinary incontinence, and the "routine" one establishes to protect himself from or conceal his incontinence. This category also includes the subjective burden felt by men who experience loss of urinary control. Men expressed feelings of embarrassment, shame, worry, resignation and overall emotional distress related to their problems with urinary function. Although this was most true for those who experienced extensive incontinence, others who had difficulties with urgency and frequency similarly expressed concerns, especially in relationship to the interruption of 'normal' social and professional activities.

The second general category we identified is the *explanation of urinary problems*. It includes issues of agency and etiology. Men differed in how they explained their urinary dysfunction in terms of who or what is responsible for the malady, to what the man attributes the cause and to what extent they themselves have control over what occurs in their daily lives. Some men blamed themselves for the choice of treatment, most often surgery, that left them incontinent. Others blamed the surgeon whose, 'slip of the knife,' or incompetence caused the incontinence. Further some men stated that they were unaware of the possibility of incontinence with a given treatment, or were unaware the extent to which this would occur. Others described independent management of the problems, making do with pads or clamps, dark pants or careful planning and proceeding through their lives.

**Bowel dysfunction** was less frequently described, however resulted in much of the same issues as urinary loss of control. For those who did, the impact was significant; men described embarrassing situations and concerns about others discovering that they were incontinent of feces, as well as significant pain associated with this. In addition, men who experienced bowel dysfunction often described pain associated with radiation proctitis and this often prohibited participation in social activities.

Erectile Dysfunction and other changes in sexual function that result from prostate cancer treatment can affect men's sexuality in complex ways. We sought to describe how the men we interviewed constructed their sexuality. We identified eight general aspects. First, and perhaps fundamentally, they referred to sexuality in terms of a *bodily function* that was, or could have been, altered as a result of surgery, radiation or hormone therapy. Sexuality entailed certain bodily mechanics. While sexuality is often appreciated in these terms, with a focus on erectile capability, the other seven aspects of sexuality define aspects of behavior, disability, interpersonal relationships, and self-image. We identified three attributes of sexuality relating to the accomplishment of physical sexual expression. The men we interviewed distinguished sex as bodily function from *drive*, that is, their desire, interest, and motivation relating to sex, and *sexual intimacy*, which could, but need not, include intercourse. Drive could be characterized as a quality of consciousness or, for some, a more visceral attribute, such as a man's natural chemistry. References to sexual intimacy included actual and potential sexual performance, including feelings of both confidence and anxiety about engaging in intimate behavior. In connection with performance issues, we also noted references to the use of *assistive devices*, including medications and mechanical devices to promote erectile function. These devices could be either helpful and restorative or cumbersome reminders of a loss of natural capability that diminished the enjoyment of sexual intimacy.

Two attributes of sexuality addressed the interpersonal context in which it was embedded by most of the men we interviewed. Distinct from references to sexual intimacy, these men described sexuality as essentially *relational*. They highlighted the ways in which sexuality entailed complex relationships with spouses, partners, and women who could be partners. These other people could be accepting and supportive, critical, challenging or rejecting. For some men, their sense of where they stood as respectable men in their interactions with women was radically altered. In addition, the men expressed varying orientations to *disclosure* of their altered sexuality. Clearly, American society defines many, complicated rules for sharing thoughts, feelings, and interests about sexuality. The men we interviewed indicated that they were constrained by these norms. They also reported new problems relating to the management of potentially stigmatizing information about themselves.

Their constructions of their sexuality entailed constructions of their overall *vitality* and their *masculinity*. With respect to vitality, sexuality was depicted as a principal component of physical well being, viewed as a normal loss that comes with age, or a sign of becoming decrepit prematurely. Put in terms of vitality, the men could be either sanguine or distressed. Moreover, sexuality could be depicted as either central to a man's evaluation of his vitality, or explicitly marked as peripheral as some indicated continued or even renewed vitality, in spite of diminished sexual capability. Finally, men expressed sexuality as an aspect of their masculine identity. Again, some men cast sexuality as essential to being a man, while others assigned it a relatively minor role. For those men who expressed sexuality as essential to their sense of self as men, several sought other ways to express their masculinity. Their loss of sexual function was challenging emotionally and often this was not something they discussed with their providers and sometimes not even with their significant others.

### Social Context

Men's stories about prostate cancer extended far beyond their own physical function or health. Their prostate cancer stories include many aspects of their social world, whether it be in

regards to decision making, going through treatment, or coping with side effects. The social world brought to bear included their intimate partner, family, friends, different members of the medical world and the doctors who treated them and see them for follow-up for prostate cancer. Further included were discussions about public discourse about prostate cancer (ie the newspaper reports, internet, and magazine articles) and men's spiritual or religious worlds. I will focus here on the how men portrayed the medical world and their doctors in relationship to their prostate cancer experiences.

Three dimensions were identified in regards to the ways men saw the medical world:

- 1) *Familiarity vs. Strangeness* – this captures differences in knowledge and familiarity with the medical world, including doctors and hospitals. That is for some men, the medical world was something they knew, they understood how it worked. This may have been because of past experience or because of professional experience. For others, entering into the medical world is like entering into a different culture, with a foreign language, set of rules and way of functioning.
- 2) *Trustworthy vs. suspect* – this captures differences in how men viewed the medical establishment as either “something noble and to be trusted” as opposed to something to be skeptical of. Some men inherently trusted the medical world to do what was best, while others were more skeptical of the motives of physicians and hospitals, insurances and health plans.
- 3) *Patient focused vs. professional focused* – this captures differences in the benevolence of the medical establishment. Is it in the best interest of the patient or is it mostly bureaucratic or businesslike or even dehumanizing. Issues of good vs. poor communication were also noted, with some men complaining that their physicians never warned them of the potential side effects, or that their physicians were unsympathetic to the problems they faced post treatment. Others were more satisfied with their physicians' communication, saying that they were able to work with their physicians to manage both the cancer and the treatment side effects

In addition we examined segments referring to doctors specific to the man's prostate cancer care. Here we identified 8 different roles that patients ascribed to the doctors they worked with:

- 1) *Discoverer*: The doctor as one who discovers the cancer, discloses the diagnosis, delivers the news, performs the PSA or biopsy and discloses the results.
- 2) *Informant*: The doctor is one who is responsible for providing information and explanations, and presents the alternatives and their implications.
- 3) *Reference link*: The doctor is a gatekeeper, facilitator of referrals to others
- 4) *Guider*: the doctor points the way towards sources of information and provides guidance as to what one should do. He may further dictate or direct what the man should do.
- 5) *Ratifier*: The doctor ratifies the patients' choice of treatment; provides authoritative sanction
- 6) *Supporter*: The doctor provides emotional support and reassurance.
- 7) *Provider*: The doctor is merely the provider of treatment services
- 8) *Collaborator*: The doctor is a partner, helping the man make decisions, working with the man to deal with treatment side effects.

As men presented their accounts, most included some aspect of those in the medical world they encountered, both in regards to prostate cancer, as well as in other medical encounters.



These perspectives on physicians and the medical world varied and the ways in which they portrayed the roles of their physicians may be of particular interest when considering issues of joint decision making.

### **Identity**

We identified segments in which men discussed issues of masculinity, of their identities as workers or professionals, as family men and breadwinners, as well as segments in which they identified issues of feeling that they had changed since they had been diagnosed and treated. Many of the issues discussed surrounded concerns about men's sense of being a man in the face of the lack of control associated with urinary incontinence and the inability to engage in sexual activity in the way they had in the past. For example, a 72 year old white married man who had undergone prostatectomy explained how both erectile and urinary problem affected his sense of himself as a man:

Man: Yes, but I mean it's not so much the incontinence, but I now don't stand when I go to the bathroom. I go to the bathroom like a woman does because you know, I can't zip down my pants. I've got Depends, I've got a clamp and all that, so I always have to look for a stall.

I: Did sitting feel funny to you?

Man: It did at first. I mean, at first everything-- You know, I thought I've lost my manhood. You know, I can't get an erection, I can't-- And this-- ... So, uh, I don't enjoy it. I'd give anything if I wasn't, but you know, I can-- As Dr. Jones said, your quality of life isn't bad. Well, I guess it isn't bad. But, uh, he doesn't know what I've done to make it not so bad. Nobody would understand it until they went through it.

In this segment, this man clearly identifies both the erectile dysfunction and the activities he needs to engage in to manage his incontinence as challenging his sense of masculinity.

Other men also discussed the impact of these problems on their masculinity. In their discussions they often sought ways to display themselves as 'men' to the interviewer. They relied not only on being able to have sex, or control their urine for their sense of identities, but in the face of these challenges to their masculine identities, men often discussed other valued masculine identities and valued life identities. In their presentation of themselves, men presented themselves as successfully maintaining a masculine and cogent self, despite the infelicities presented by the cancer treatment. Thus men presented themselves as professionals or workers, breadwinners, family men, providers for their families, active in their communities, and as good husbands.

This aspect of men's experience with prostate cancer is crucial for understanding what it might mean for someone to be a prostate cancer survivor. While some men explicitly discussed being 'a survivor,' others implicitly revealed the ways in which they are moving forward in their lives. It may be that good survivor care not only focuses on remediating the failings of the body, but refocusing men on aspects of themselves that help them maintain their sense of self in the face of challenges.

Task 5: Complete final report, Months 35-36.

Pending completion of analyses.

## KEY RESEARCH ACCOMPLISHMENTS

### Additional Analysis of Survey Data Collected in Completing Task 2

The 33-page questionnaire included a comprehensive set of bodily dysfunction and quality of life measures. The two outcomes of interest in the present study, perceived cancer control and perceptions of one's treatment decisions, were measured by multi-item scales: *Cancer Control* and *Informed Decisions*. Nine other scales assessed additional psychosocial dimensions of prostate cancer-related quality of life. Behavioral, emotional, and interpersonal effects of urinary and bowel dysfunction (e.g., feelings of embarrassment, helplessness; preoccupation with need to urinate or monitor bowels) were assessed by *Urinary Control* and *Bowel Control*. Effects of sexual dysfunction on sexual behavior and self image were assessed by *Sexual Intimacy* (e.g., awkwardness with sexual intimacy and performance), and *Sexual Confidence* (e.g., comfort with one's sexuality). The broader effects of bodily—especially sexual—dysfunction were assessed by *Masculine Self-Esteem* (e.g., feeling oneself to be weak, small or less than a whole man). Related concerns about the relationship with one's spouse or intimate partner (e.g., misgivings about diminished bonds of affection) were assessed by *Spouse Affection*. Feelings of apprehensiveness about future health problems expressed by prostate cancer survivors were assessed by *Health Worry*, while attention to PSA and the comfort of knowing one's PSA level were assessed by *PSA Concern*. Summary appraisals of the success of one's coping with prostate cancer were assessed by *Outlook*. *Regret* relating to the choice to pursue a particular course of was defined by five items that captured feelings of having made the wrong choice of treatment and a wish to revisit and change that decision.

*Cancer Control*, *Informed Decision*, and the nine other prostate cancer-related quality of life scales were developed as a set of patient-centered measures of the outcomes of treatment for early prostate cancer.(1) These scales encompass aspects of behavior and well-being beyond the relatively restricted definition of quality of life provided by measures of the severity of physical symptoms. Scores on *Cancer Control*, *Informed Decision*, and the other nine prostate cancer-related quality of life scales ranged from 0 to 100, with high scores indicating higher levels quality of life, except for *Health Worry* and *PSA Concern*, where high scores indicated greater worry or concern. The measure of regret, which fortunately is denied by most men, is a dichotomous variable, with men who express relatively frequent feelings of regret scored as regretful.

Diagnostic data, including pre-treatment PSA, Gleason score, and stage, and primary treatment, were derived from medical record review. Treatments received subsequent to the first six months following diagnosis, including androgen deprivation and treatments received at sites other than those where study participants had been recruited, were assessed by self report. Androgen deprivation therapy was ascertained by asking men whether they "had started a long term course of hormone treatment (injections or pills) for more than 12 months or that you continue to receive" or had undergone "an operation in which your testicles were removed (an orchiectomy) in the months or years after the first six months following diagnosis. PSA levels subsequent to primary treatment were assessed by self report, using items developed by Fowler and his coworkers in their survey Medicare beneficiaries undergoing androgen deprivation.(2)



The data analysis was focused on examining variation in two scales: Cancer Control and Informed Decision. The distributions of scores on these scales, shown in Figure 1, indicated substantial ceiling effects and negative skew, as had been found in previous survey data.(3) Hence, both of these scales were reduced to three-level ordinal measures. Scores equal to or greater than 80 were considered "high," scores between 60 and 79, inclusive, were "medium," and scores less than 60 were "low." These cutpoint correspond to responses to the items comprising these scales, including positive and negative statements that could be endorsed or rejected on a five point scale. A score of 80 or higher on these scales indicates that on average a respondent tended to answer with a strong endorsement (i.e., "very much") of positive statements and a strong rejection (i.e., not at all) of negative statements defining the scales. Conversely, a score of 60 or less indicates that responses to positive statements were equivocal (i.e., "somewhat") or a rejection, while responses to negative statements were equivocal or strongly endorsed.

We examined univariate associations between these two scales and demographics, diagnostic variables, treatment, subsequent PSA, urinary, bowel, and sexual dysfunction and bother, and prostate cancer-related quality of life. Associations with categorical variables were evaluated using chi-square, while the median test was used to test associations with age at diagnosis and years since treatment. Associations with symptom indexes, bother scales, and quality of life scales were evaluated using Spearman's correlation coefficients for ordinal variables.

In order to evaluate the joint effects of these variables we estimated ordinal logistic models for Cancer Control and then for Informed Decision. Models were built systematically in four steps. In the first step, we evaluated the effects of demographic, diagnostic, and treatment variables with at least marginally significant ( $p < .10$ ) univariate associations with the outcome. We used a stepwise procedure with backward elimination in which variates with non-significant coefficients ( $p < .05$ ) were deleted. In the second step, we evaluated the effects of treatment-related bodily dysfunction by including the symptom indexes and symptom-bother scales, along with variables retained from step 1. In the third step, we evaluated the effects of prostate cancer-related quality of life scales, along with covariates retained in steps 1 and 2. Finally, in the fourth step, we included measures of overall functional status and well-being, health perceptions, stigma, and social support, along with covariates retained in the prior three steps. In each step we included variables with significant ( $p < .05$ ) univariate associations with the dependent variable. This four step process was followed first with Cancer Control as the dependent variable and then with Informed Decision. All analyses were performed using SAS procedures.

*Results.* The response to this mail survey was quite high; 235 (87%) of 269 surviving patients for whom we could obtain valid addresses returned completed questionnaires. Ten men explicitly refused to participate, three of whom indicated they were too ill; 24 failed to return a questionnaire after being sent reminder post cards and then second questionnaires, and being contacted by telephone. The response rate is noteworthy, given the passage of time since these patients had participated in the previous cohort study. At minimum, the respondents had completed their 36-month follow-up assessments in the preceding cohort study 12 months previously. For about 30%, the interim between between that last follow-up and their receiving the present questionnaire was four or more years.

At diagnosis, these patients were median of 64 years old. Most were married and highly educated. Most had undergone either radical prostatectomy (33%) or external beam radiation

(41%), while 18% pursued brachytherapy. Most of the latter were accrued in the latter part of the cohort study, which had been extended in order observe the reemergence of this therapy for early prostate cancer in the late 1990's. Androgen deprivation therapy, subsequent to primary therapy, was reported by 15%. One-fourth said their PSA had started to go up again after their first treatment, but 66% said their doctors had most recently told them their PSA was stable and 37% reported virtually undetectable PSA.

Most of these men expressed a comfortable understanding that their prostate cancer was under control. It was not an object of significant concern for 66% of the respondents, who indicated by high scores on *Cancer Control*, illustrated in Figure 1. A slightly smaller proportion of these men, 57%, indicated high confidence in their treatment decisions, feeling that they were well informed and satisfied with their choices. Conversely, 14% reported low levels of cancer control and 15% reported poorly informed decisions. Cancer control and decision confidence overlapped somewhat; 43% reported both high levels of cancer control and informed decision, while 21% expressed misgivings (i.e., low to moderate scores) about both cancer control and the quality of their decision making (data not shown). The correlation between these two outcomes was modest:  $r = .32$ .

Perceived cancer control was associated with satisfaction with treatment for prostate cancer and global appraisals of its outcomes, that is, "with the way things have turned out since you found out you had prostate cancer." Patients' confidence in their treatment decisions was also associated with satisfaction with treatment and overall outcomes. Conversely, diffidence in decisions had a marked association with regret. While 7% of the total sample expressed regret, 23% of those who felt their treatment decisions were poorly informed wished they had chosen a different approach. In addition, feelings about the quality of one's treatment decisions were associated with responsibility for the decisions as recalled, as men feeling little confidence more likely to assign greater responsibility to their doctors.

Perceptions of cancer control were negatively associated with Gleason scores from clinical biopsies performed four to eight years previously. Patients with low or moderate Cancer Control were twice as likely to report total Gleason scores greater than 7. Cancer control was not significantly related to PSA level at the time of diagnosis, but there was a clearly negative association with subsequent rises in PSA. Perceived cancer control was not significantly associated with type of primary treatment, but men survivors who were concerned about poor cancer control were much more likely to report subsequent androgen deprivation treatment.

Unlike cancer control, patients' confidence in their treatment decisions was associated with marital status and, marginally, with age. Confident men were more likely to be married and somewhat younger. Confidence in treatment decisions was also associated with the chosen treatment. Men who were who felt high confidence in their decision making were more likely to have chosen radical prostatectomy, while the diffident had more frequently chosen external beam radiation. Feelings about treatment decisions were not significantly associated with subsequent androgen deprivation, and they were not at all associated with subsequent rises in PSA. However, men who expressed misgivings about their decisions had lived with them longer time.

Both perceived cancer control and confidence in treatment decisions were associated with the severity of treatment side effects and quality of life. Only confidence in treatment decisions was associated with relevant domains of bodily function at baseline, and then only sexual function. Men who felt poorly informed and unsatisfied with treatment decisions made four to eight years before were slightly worse sexual dysfunction at the time they were making

those decisions. Current levels of urinary obstruction, but not incontinence, and bowel problems were associated with poorer scores on both outcomes. Confidence in decisions was diminished by current, post-treatment sexual dysfunction. In addition, we also evaluated associations between changes in symptom indexes, i.e., increases, from pretreatment to 24 months after treatment, when long-term complications would be stable, and these two outcomes. Neither Cancer Control nor Informed Decision scores were associated with *increased* urinary, bowel or sexual dysfunction in these long term survivors.

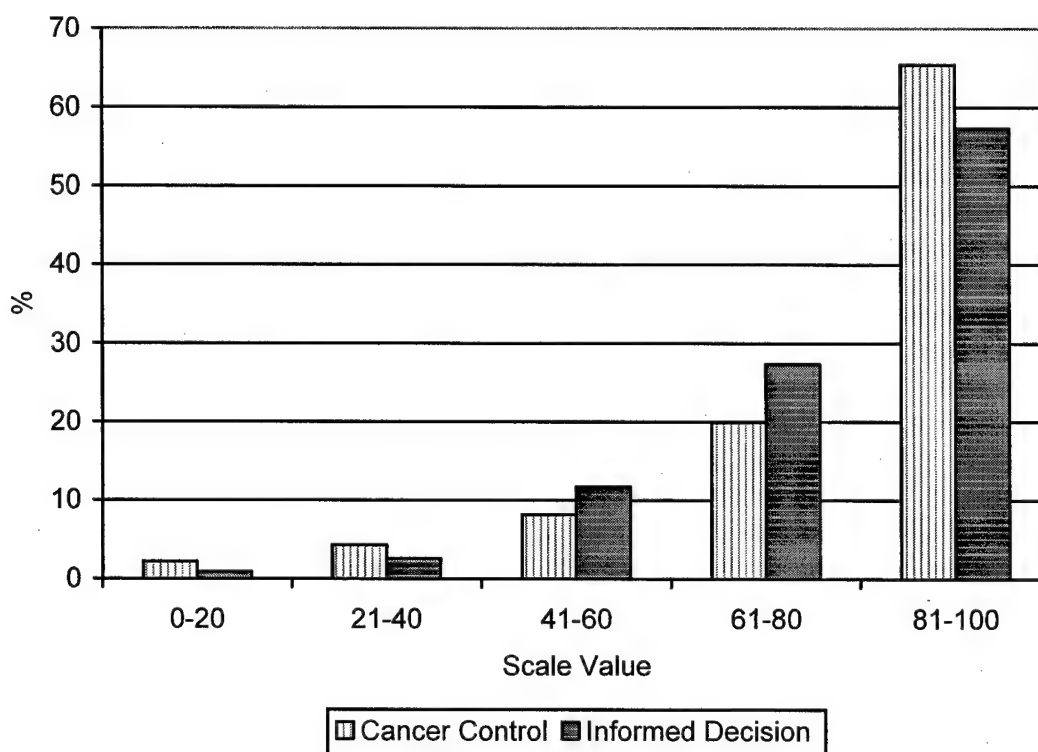
Relatively poorer prostate cancer-related quality of life was associated with lower levels of perceived cancer control and greater diffidence in treatment decisions. In particular, *Health Worry*, which indicates apprehensiveness about possible bad news about one's health in the future, including cancer recurrence, was strongly correlated with perceived cancer control ( $r = -.56$ ). However, neither PSA concern nor appraisal of the effect of surviving cancer on one's outlook were significantly associated with perceived cancer control. Both of these dimensions of quality of life were positively correlated with confidence in decisions. *Sexual Confidence* and *Martial Function* were associated with greater confidence in treatment decisions. Behavioral and emotional problems associated with poor bowel control were associated with greater misgivings about cancer control.

Confidence in decisions was positively associated with both pre-treatment and current/follow up physical health, as measured by the Physical Component Summary of the SF-36, while current mental health increased with increasing perceived cancer control. Both outcomes were also aligned with more optimistic health outlook, greater social support, and less feelings of stigma.

The multivariable models that were constructed to examine the joint effects of these variables on *Cancer Control* and *Informed Decision* are presented in Tables 2 and 3. The likelihood of a high level of perceived cancer control was decreased by a pretreatment Gleason score of 7 or greater, androgen deprivation therapy, and evidence of PSA failure, including a rising PSA after initial treatment, being told by one's doctor that one's PSA is rising, and a current PSA greater than 1.0. In the multivariable model, bother with bowel symptoms also associated with diminished decreased cancer control, but univariate associations with severity of bowel symptoms and urinary obstruction failed to remain significant. In addition, sexual confidence was associated with increased cancer control. However, this effect, along with that of bowel bother, was reduced to insignificance when health worry was considered in the model. Overall mental health status, other health perceptions, stigma, and social support had no significant independent effects on cancer control, relative to pre-treatment Gleason score and subsequent androgen deprivation and rising PSA.

A different picture emerged in developing a model to account for confidence that one's treatment decisions were well informed. The likelihood of confidence increased with being married and having chosen radical prostatectomy or brachytherapy, rather than external beam radiation. Bother with sexual dysfunction reduced confidence, while other measures of dysfunction and bother had relatively no effect. Masculine self esteem and PSA concern were both associated with greater probability of high confidence. However, the effect of masculine self esteem attenuated when social support and health worry, both with strong effects, were considered in the model. Conversely, stigma and perceived physical health had no independent effects on how men perceived the quality of their treatment decisions.

Since the univariate analysis indicated that Spouse Affection and the MOS Marital Function scales were significantly associated with the two outcome variables, two additional sets of models were developed to evaluate the effects of these variables in conjunction with other covariates. These models were restricted to the subset of patients who were married or had a person they identified as being like a spouse; marital status was not included in the models. The final models were similar to those obtained with the full sample. Spouse Affection was retained as a significant determinant of cancer control, along with sexual confidence, health worry, pretreatment Gleason score, androgen deprivation, and post-treatment rising PSA. In the case of Informed Decision, Marital Function was a significant determinant of a high score, along with choice of radical prostatectomy or brachytherapy, and sexual dysfunction, although the effect was diminished to nonsignificance with the addition of social support and health worry.



**Figure 1. Distributions of Scores on Cancer Control and Informed Decision Scales**

<b>Table 2. Summary of Sequential Stepwise (backward) Logistic Model: Cancer Control</b>								
	coeff	p	coeff	p	coeff	p	coeff	p
Gleason = 7	-.89	.007	-1.09	.002	-1.06	.003	-1.13	.016
Androgen deprivation	-.92	.023	-1.17	.007	-.79	.082	-1.31	.016
PSA went up	-1.06	.002	-.92	.012	-1.21	.002	-.98	.029
PSA rising	-2.07	<.001	-2.03	<.001	-1.79	<.001	-1.78	.001
PSA > 1.0	-.86	.009	-.91	.009	-.87	.017	-.65	.100
Bowel bother			-.03	.018	-.02	.068	-.01	.405
Sexual confidence					.02	.004	.01	.27
Health worry							-.08	<.001
c statistic	.764		.792		.792		.870	
Variables Removed	Gleason > 7		urinary obstruction bowel dysfunction		urinary control bowel control sexual intimacy masculine self esteem		MCS 12 health outlook health change stigma social support	

<b>Table 3. Summary of Sequential Stepwise (backward) Logistic Model: Well Informed Decision</b>								
	coeff	p	coeff	p	coeff	p	coeff	p
married	.75	.030	.81	.035	.84	.031	.47	.235
radical prostatectomy	.81	.008	.86	.009	.78	.017	.82	.018
brachytherapy	1.49	.001	1.58	.001	1.62	.001	1.69	.001
sexual bother			-.01	.006	-.01	.066	-.01	.157
masculine self esteem					.03	.003	.01	.427
PSA concern					.01	.021	.01	.010
social support							.03	<.001
health worry							-.03	.005
c statistic	.654		.682		.740		.787	
Variables Removed	external radiation years since treatment		baseline sexual dysfunction urinary obstruction bowel dysfunction bowel bother sexual dysfunction		bowel control sexual intimacy sexual confidence effect of cancer on outlook		PCS-baseline PCS-follow up health outlook stigma	

## REPORTABLE OUTCOMES

Interim findings provide verification of psychosocial dimensions of prostate cancer-related quality of life, as reported in recently published findings from our previous research.<sup>1</sup> Preliminary analyses of interviews suggest that we will be able to explore and explicate life changes, suggested in recent analyses of cross-sectional survey data, through planned analyses of men's narratives.<sup>2</sup>

The research team has been expanded by the addition of Dr. Lorrie Powel. Her study of quality of life outcomes associated with post-prostatectomy urinary incontinence has been supported by DoD as a post-doctoral training grant, under the supervision of Dr. Jack A. Clark (DAMD17-02-1-0236). Dr. Powel brings extensive clinical experience in nursing to the project.

While Dr. Powel's project is a separate undertaking, her training will include participation in the analysis of data collected in the present study. In addition, Dr. Barbara G. Bokhour, co-investigator, has recently completed the first year of a two-year study, funded by the National Cancer Institute (RO3 CA 91737001), to explore the clinical utility of the qualitative findings derived from the present study. As a result, the overall project has been strengthened by clinical expertise and an direct examination of the clinical utility of the findings, as they emerge.

### Presentations:

Bokhour, BG and JA Clark. *Quality of Life and Sexuality after Prostate Cancer*. The Fifth Annual Massachusetts Prostate Cancer Symposium, May 2002. Marlborough, MA

Bokhour, BG *No less a man: Men's stories of surviving prostate cancer*. American Association of Applied Linguistics Annual Conference, March 2003. Arlington, VA.

Bokhour, BG *"Part of me is not what it used to be": Reconstructing identity in early prostate cancer*. Eighth Annual Language and Social Interaction in Communication Round Table, October 2001, West Greenwich, Rhode Island

Bokhour, BG and JA Clark. *Men's stories of surviving prostate cancer*. Cancer Survivorship: Resilience Across the Lifespan. National Cancer Institutes and American Cancer Society. June 2002, Washington, DC

Bokhour, BG. *Prostate cancer survivor narratives and doctors' responses*. Small grants program for behavioral research in cancer control, National Cancer Institute, December 2002. Bethesda, MD

Clark J, Talcott J. *Decisions and Cancer Control: Perceptions of Prostate Cancer Survivors*. Presentation at the Annual Meeting of the Department of Veterans Affairs Health Services Research and Development Service, Washington, DC, March 2004.

#### Manuscripts in Preparation:

Bokhour, BG and JA Clark (in preparation) *No Less a Man: Reconstructing Identity after Prostate Cancer* to be submitted as part of a special issue of *Communication & Medicine: Constructing Identity in Medical Discourses*

Bokhour, BG and JA Clark (in preparation) *Caring for survivors of prostate cancer: The practice of primary care physicians and urologists.* to be submitted to *Journal of General Internal Medicine*.

Clark J, Talcott J. Long after a Diagnosis of Early Prostate Cancer: Survivors' Perceptions of Cancer Control and their Treatment Decisions to be submitted to *Cancer*

#### **CONCLUSIONS**

Subject accrual was accomplished as expected at the Buffalo site in completing Task 3. However, subject accrual was not successfully initiated at the Washington DC site because of substantial delays in the granting of final approval by the local IRB. The IRB was audited by the VA in the Fall and Winter of 2001/2002, resulting in significant delays in the processing of protocols. While we had anticipated that this problem would be resolved, our expectations were not met. We explored and secured the participation of an additional site in order to meet subject accrual goals: the urology clinic at Boston Medical Center. The investigators have a relationship with this clinic, developed in previous studies. The clinic also serves a racially and economically diverse population, thus it would be suitable to the goals of the study, including analyses of quality of life changes associated with treatment for early prostate cancer in a diverse population.

The results of this study will be useful in several ways. They will guide the design of future, large scale studies of the processes and outcomes of care for early prostate cancer. Yet, they will have more immediate utility. They will provide informative materials for health care providers about the significant changes men see themselves as undergoing. They will also provide information to men who face the ominous diagnosis and those who continue to live with the outcomes of their treatment. Moreover, we will provide information about the changes men experience in the understandable form of men's stories.

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## **APPENDICES**

### **Survey Questionnaire Used in Accomplishing Task 2**

## Section One: Treatment for Your Prostate Cancer

The questions in this section ask about the treatment you have received for prostate cancer. First, we ask about treatment during the first 6 months after getting the diagnosis. Since your situation may have changed, we will then ask about your treatment in the years after the first 6 months following your diagnosis.

1. What treatments did you receive during the first 6 months after your prostate cancer was diagnosed?  
Please answer every question, 1a through 1h below, since every man's case is unique and sometimes more than one treatment appears necessary.

	Yes	No
a. Did you decide not to do anything for the time being (watch and wait)?	1	2
b. Did you have an operation to remove your prostate (a radical prostatectomy)?	1	2
c. Did you have a procedure in which radioactive seeds were implanted in your prostate (brachytherapy)?	1	2
d. Did you receive a course of daily radiation treatment (external beam radiation)? This may be done by itself or added after surgery or radioactive seeds (brachytherapy).	1	2
e. Did you have a procedure in which your prostate was frozen (cryotherapy)?	1	2
f. Did you receive a <i>brief course (less than 1 year)</i> of hormone treatment (injections, pills or both) around the time you were diagnosed, or along with another treatment, such as surgery, radiation or seeds?	1	2
g. Did you start a long-term course of hormone treatment (injections, pills or both) for more than 12 months or that you continue to receive?	1	2
h. Did you have an operation in which your testicles were removed (an orchiectomy)?	1	2

2. During the first 6 months, how many doctors did you talk to about how your prostate cancer should be treated?

Write in number of doctors

Yes	No
1	2

3. During the first 6 months, did any doctor you talked to offer you a choice between two or more types of treatment for your prostate cancer?

4. During the first 6 months, did you get different recommendations about the best treatment from different doctors you talked to?

Yes, I got different recommendations	No, all doctors recommended the same treatment	I talked to only one doctor
1	2	3

5. Each man and his doctor may reach the decision on which treatment a man should get for early prostate cancer in a different way. Which statement best describes how the treatment you received **during the first 6 months** was chosen?

The choice was mostly my doctor's; my doctor made the decision or made a strong recommendation	My doctor and I came to the decision together	The choice was mostly mine; my doctor left the decision entirely or mostly up to me
1	2	3

**Treatment for your prostate cancer since the first 6 months.**

6. After your first treatment for prostate cancer, did your PSA ever start to go up again?

Yes	No	Don't Know
1	2	3

7. The last time you heard from your doctor, what was your PSA doing?

Falling	Staying the same	Rising	Don't Know
1	2	3	4

8. What was your **most recent** PSA result?

	<b>Write in the approximate number</b>
	Don't know; check here

**Treatment for your prostate cancer since the first 6 months.**

9. In the years following the first 6 months after diagnosis, what treatments have you received?

Since every man's case is unique and more than one treatment may be necessary at different times, be sure to mark an answer for each of these questions, 8a through 8h.

	Yes	No
a. Did you decide not to do anything for the time being (continue to watch and wait)?	1	2
b. Did you have an operation to remove your prostate (a radical prostatectomy)?	1	2
c. Did you have a procedure in which radioactive seeds were implanted in your prostate (brachytherapy)?	1	2
d. Did you receive a course of daily radiation treatment (external beam radiation)? This may be done by itself or added after surgery or radioactive seeds (brachytherapy).	1	2
e. Did you have a procedure in which your prostate was frozen (cryotherapy)?	1	2
f. Did you receive a <i>brief course (less than 1 year)</i> of hormone treatment (injections, pills or both) around the time you were diagnosed, or along with another treatment, such as surgery, radiation or seeds?	1	2
g. Did you start a long-term course of hormone treatment (injections or pills) for more than 12 months or that you continue to receive?	1	2
h. Did you have an operation in which your testicles were removed (an orchiectomy)?	1	2

## Section Two: Urinary Problems

1. In the past week, how easy has your urine flow been?

Very easy	Fairly easy	Slow, but I don't have to strain or bear down	Slow, and I do have to strain or bear down	Very slow, and I have to strain or bear down hard
1	2	3	4	5

2. In the past week, how often did you urinate at night?

Seldom or never	Once a night	2 to 3 times a night	More than three times a night
1	2	3	4

3. In the past week, how often did you urinate?

4 or fewer times a day	5 to 8 times a day	9 to 12 times a day	More than 12 times a day
1	2	3	4

4. In the past week, how often have you felt pain or burning during urination?

Not at all	Occasionally	Fairly frequently	Frequently	Very frequently
1	2	3	4	5

5. In the past week, how often have you urinated blood?

Not at all	Occasionally	Fairly frequently	Frequently	Very frequently
1	2	3	4	5

6. In the past week, how often did you have the feeling that it is urgent that you pass your urine?

Not at all	Occasionally	Fairly frequently	Frequently	Very frequently
1	2	3	4	5

7. In the past week, how much control did you have over your urine?

Had complete control (no leaking)	Leaked urine, but only at certain times	Leaked urine most of the time	Little or no control
1	2	3	4

8. In the past week, how often did you leak urine?

Not at all	Occasionally	Fairly frequently	Frequently	Very frequently
1	2	3	4	5

9. IF YOU LEAKED URINE IN THE PAST WEEK, how much usually comes out?

Had complete control (no leaking)	A few drops	Less than a tablespoon	More than a tablespoon	Can't tell how much
1	2	3	4	5

Yes	No
1	2

10. In the past week, did you wear a pad to absorb urine in your underwear?

10a. In the past week, if you wore a pad in your underwear, how often during the day did you change it?

Not at all	Once or twice a day	Three or more times a day	Did not wear a pad
1	2	3	4

11. How big a problem, if any, has each of the following been for you during the past 4 weeks?

	No Problem	Very Small Problem	Small Problem	Moderate Problem	Big Problem
a. Dripping or leaking urine	1	2	3	4	5
b. Pain or burning on urination	1	2	3	4	5
c. Bleeding with urination	1	2	3	4	5
d. Weak urine stream or incomplete emptying	1	2	3	4	5
e. Waking up to urinate	1	2	3	4	5
f. Need to urinate frequently during the day	1	2	3	4	5

12. Overall, how big a problem has your urinary function been for you during the past 4 weeks?

No problem	Very small problem	Small problem	Moderate problem	Big problem
1	2	3	4	5



Questions 13a – 13q ask about how you may feel about **urinary problems** and how they may affect your life. If you have no problems at all in these areas, simply circle the number under "not at all."

13. How true has each of the following statements been for you during the past 4 weeks?

	Not at All	A Little Bit	Somewhat	Quite a Bit	Very Much
a. I worry about wetting myself.	1	2	3	4	5
b. I worry about coughing or sneezing making me lose control.	1	2	3	4	5
c. I worry about others smelling urine on me.	1	2	3	4	5
d. I am careful to watch for any signal that I need to urinate.	1	2	3	4	5
e. I am careful not to laugh, for fear of losing control.	1	2	3	4	5
f. Leaking urine makes me feel dirty.	1	2	3	4	5
g. I am sometimes embarrassed or humiliated because of my urinary problems.	1	2	3	4	5
h. I'm often afraid of having an accident and making a mess.	1	2	3	4	5
i. My urinary problems make me feel helpless.	1	2	3	4	5
j. I feel nervous when I don't know where the bathrooms are.	1	2	3	4	5
k. The need to urinate is never far from my mind.	1	2	3	4	5
l. I can rely on my body to warn me that I need to urinate soon enough.	1	2	3	4	5
m. My urinary problems complicate everything I do.	1	2	3	4	5
n. The things I have to do to just to urinate are embarrassing.	1	2	3	4	5
o. I avoid situations in which I might not be able to get to a bathroom in time.	1	2	3	4	5
p. My urinary problems have affected my enjoyment of life.	1	2	3	4	5
q. Urination makes me miserable.	1	2	3	4	5

## Section Three: Bowel Problems

The questions in this section ask about bowel problems that may be caused by various physical conditions.

1. In the past week, how often did you have diarrhea, or loose, watery stools?

Not at all	Occasionally	Fairly frequently	Frequently	Very frequently
1	2	3	4	5

2. In the past week, how often did you have a sense of urgency that you move your bowels?

Not at all	Occasionally	Fairly frequently	Frequently	Very frequently
1	2	3	4	5

3. In the past week, how often did you have tenderness or pain when you move your bowels?

Not at all	Occasionally	Fairly frequently	Frequently	Very frequently
1	2	3	4	5

4. In the past week, how often did you have bleeding with your bowel movements?

Not at all	Occasionally	Fairly frequently	Frequently	Very frequently
1	2	3	4	5

5. In the past week, how often did you have abdominal cramping or pain?

Not at all	Occasionally	Fairly frequently	Frequently	Very frequently
1	2	3	4	5

6. In the past week, how often have you passed mucus from your rectum?

Not at all	Occasionally	Fairly frequently	Frequently	Very frequently
1	2	3	4	5

7. In the past week, how often did you have the feeling that you have an urge to move your bowels, but have nothing to pass?

Not at all	Occasionally	Fairly frequently	Frequently	Very frequently
1	2	3	4	5

8. How big a problem, if any, has each of the following been for you during the past 4 weeks?

	No Problem	Very Small Problem	Small Problem	Moderate Problem	Big Problem
a. Urgency to have a bowel movement	1	2	3	4	5
b. Increased frequency of bowel movements	1	2	3	4	5
c. Watery bowel movements	1	2	3	4	5
d. Losing control of your stools	1	2	3	4	5
e. Bloody stools	1	2	3	4	5
f. Abdominal/pelvic/rectal pain	1	2	3	4	5

9. Overall, how big a problem have your bowel habits been for you during the past 4 weeks?

No problem	Very small problem	Small problem	Moderate problem	Big problem
1	2	3	4	5

Questions 10a – 10h ask about how you may feel about **bowel problems** and how they may affect your life. If you have no problems at all in these areas, simply circle the number under "not at all."

13. How true has each of the following statements been for you during the past 4 weeks?

	NOT AT ALL	A LITTLE BIT	SOMEWHAT	QUITE A BIT	VERY MUCH
a. I worry about soiling myself.	1	2	3	4	5
b. I am careful to watch for any signal that I need to have a bowel movement.	1	2	3	4	5
c. My bowel problems make me feel helpless.	1	2	3	4	5
d. I feel nervous when I don't know where the bathrooms are.	1	2	3	4	5
e. The need to move my bowels is never far from my mind.	1	2	3	4	5
f. I can rely on my body to warn me that I need to have a bowel movement soon enough.	1	2	3	4	5
g. My bowel problems complicate everything I do.	1	2	3	4	5
h. My bowel problems have affected my enjoyment of life.	1	2	3	4	5

## Section Four: Sexual Functioning

1. In the past 4 weeks, how interested in sex have you been?

Not at all	Slightly	Moderately	Quite a bit	Extremely
1	2	3	4	5

2. In the past 4 weeks, how often have you felt sexual desire?

Almost never/never	A few times (less than half the time)	Sometimes (about half the time)	Most times (more than half the time)	Almost always/always
1	2	3	4	5

3. In the past 4 weeks, how would you rate your level of sexual desire?

Very low/none at all	Low	Moderate	High	Very high
1	2	3	4	5

4. In the past 4 weeks, have you had any erections at all (including morning erections)?

Yes	Yes, morning erections only	No
1	2	3

5. In the past 4 weeks, what is the most erect (or hard) your penis has become at any time?

Full erection	Nearly full erection - sufficient for penetration without manual assistance	Partial erection - capable of penetration with manual assistance	Partial erection - not capable of penetration even with manual assistance	No erection at all
1	2	3	4	5

6. In the past 4 weeks, what is the most erect (or hard) your penis has become at any time without the use of Viagra, Erec-Aid or any other type of erection aid?

Full erection	Nearly full erection - sufficient for penetration without manual assistance	Partial erection - capable of penetration with manual assistance	Partial erection - not capable of penetration even with manual assistance	No erection at all
1	2	3	4	5

7. In the past 4 weeks, how much difficulty have you had getting an erection during sexual activity?

A lot	Some	A little	No difficulty	Have not had sexual activity
1	2	3	4	5

8. In the past 4 weeks, how much difficulty have you had keeping an erection during sexual activity?

A lot	Some	A little	No difficulty	Have not had sexual activity
1	2	3	4	5

9. In the past 4 weeks, have you been able to reach orgasm (sensation of climax)?

Yes, all the time	Yes, some of the time	No, not at all	Have not engaged in sexual activity in the past 4 weeks
1	2	3	4

10. In the past 4 weeks, have you been able to ejaculate?

Yes, all the time	Yes, some of the time	No, not at all	Have not engaged in sexual activity in the past 4 weeks
1	2	3	4

11. In the past 4 weeks, how satisfied have you been with your sex life?

Extremely satisfied	Somewhat satisfied	Neither satisfied nor dissatisfied	Somewhat dissatisfied	Extremely dissatisfied
1	2	3	4	5

12. In the past 4 weeks, how much have you cared about having an active sex life?				
Not at all	A little	Some	A lot	
1	2	3	4	

13. How big a problem, if any, has each of the following been for you during the past four weeks?						
	No Problem	Very Small Problem	Small Problem	Moderate Problem	Big Problem	
a. Your level of sexual desire	1	2	3	4	5	
b. Your ability to relax and enjoy sex	1	2	3	4	5	
c. Your ability to become sexually aroused	1	2	3	4	5	
d. Your ability to have an erection	1	2	3	4	5	
e. Your ability to reach orgasm	1	2	3	4	5	

13. Overall, how big a problem has your sexual function or lack of sexual function been for you during the past 4 weeks?				
No problem	Very small problem	Small problem	Moderate problem	Big problem
1	2	3	4	5



14. How true has each of the following statements been for you during the past 4 weeks?

	Not at All	A Little Bit	Somewhat	Quite a Bit	Very Much
b. I'm confident in my sexual ability.	1	2	3	4	5
c. Trying to have sex is too complicated.	1	2	3	4	5
d. My sex life feels unnatural to me.	1	2	3	4	5
e. I am able to enjoy physical intimacy.	1	2	3	4	5
f. I feel helpless to act on my sexual urges.	1	2	3	4	5
g. When it comes to getting close physically, I have to be careful not to start something I can't finish.	1	2	3	4	5
h. I am worried that I might embarrass myself if I try to have sex.	1	2	3	4	5
i. I feel good about my sexuality.	1	2	3	4	5
j. Thinking about my sex life leaves me with an uneasy feeling.	1	2	3	4	5
k. When I hear talk about sex I feel like the odd man out.	1	2	3	4	5
l. I feel good about the way I deal with my own sexual needs and desires.	1	2	3	4	5
m. It feels good to think about sex.	1	2	3	4	5
n. I would feel ill at ease if someone flirted with me.	1	2	3	4	5

New treatments have become available for problems with sexual function. Questions 15a—15f ask about your experience with these treatments.

15. Which statement best describes your experience with each of these sexual function treatments in the past 12 months?

	Have not used this in the past 12 months	Have used this and plan to use it again	Have used this, but do not plan to use it again
a. Viagra	1	2	3
b. Yohimbe	1	2	3
c. Medicine inserted into the tip of the penis (MUSE)	1	2	3
d. Erec-Aid or other vacuum device	1	2	3
e. Injection therapy (medicine injected into a vein in the penis)	1	2	3
f. Penile prosthesis	1	2	3

## Section Five: Social Relationships

1. How true has each of the following statements been for you during the past 4 weeks?

	Not at All	A Little Bit	Somewhat	Quite a Bit	Very Much
a. I avoid other people.	1	2	3	4	5
b. I feel that other people are avoiding me.	1	2	3	4	5
c. I feel odd and different from other people.	1	2	3	4	5
d. I feel self-conscious and embarrassed.	1	2	3	4	5
e. I am able to take care of the people who depend on me.	1	2	3	4	5

2. About how many close friends and close relatives do you have (people you feel at ease with and can talk to about what is on your mind)?  
Write in the number of close friends and relatives

3. People sometimes look to others for companionship, assistance or other types of support. How often is each of the following kinds of support available to you if you need it?

	None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
a. Someone to confide in or talk to about yourself or your problems.	1	2	3	4	5
b. Someone to get together with for relaxation.	1	2	3	4	5
c. Someone to help with daily chores if you were sick.	1	2	3	4	5
d. Someone to turn to for suggestions about how to deal with a personal problem.	1	2	3	4	5
e. Someone to love and make you feel wanted.	1	2	3	4	5

The following statements are about your relationship with your spouse or partner.

Yes	No
1	2

→ If NO, go to Section Seven.

4. Do you have a spouse or a partner who is like a spouse to you?

5. In the past 4 weeks, how TRUE or FALSE has each of the following statements been for you and your spouse or partner?

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a. We said anything we wanted to say to each other.	1	2	3	4	5
b. We often had trouble sharing our personal feelings.	1	2	3	4	5
c. It was hard to blow off steam with each other.	1	2	3	4	5
d. I felt close to my spouse or partner.	1	2	3	4	5
e. My spouse or partner was supportive of me.	1	2	3	4	5
f. We tended to rely on other people for help rather than on each other.	1	2	3	4	5
g. My spouse or partner is satisfied with our sex life.	1	2	3	4	5

6. How true has each of the following statements been for you during the past 4 weeks?

	NOT AT ALL	A LITTLE BIT	SOMEWHAT	QUITE A BIT	VERY MUCH
a. I feel uncomfortable when my spouse or partner acts very affectionate.	1	2	3	4	5
b. My spouse or partner seems cool and distant from me.	1	2	3	4	5
c. My partner avoids embracing, kissing or caressing me.	1	2	3	4	5
e. I feel that my spouse or partner may want to turn to others for affection.	1	2	3	4	5
g. I do a good job taking care of my spouse or partner.	1	2	3	4	5
h. My spouse or partner understands completely what I've gone through with prostate cancer.	1	2	3	4	5

7. How would you rate your spouse's health in general?

	Very Good	Good	Fair	Poor
1 Excellent	2	3	4	5

## Section Six: How You Feel About Yourself

1. How true has each of the following statements been for you during the past 4 weeks?

	Not at All	A Little Bit	Somewhat	Quite a Bit	Very Much
a. I have negative feelings about the way my body looks.	1	2	3	4	5
b. I avoid being seen without a shirt on.	1	2	3	4	5
c. I have been concerned about loss of muscle tone.	1	2	3	4	5
d. I feel that my body is getting soft and flabby.	1	2	3	4	5
e. I worry about becoming dependent on others.	1	2	3	4	5
f. I am embarrassed about my physical condition.	1	2	3	4	5
g. I worry about being compared unfavorably to other men.	1	2	3	4	5
h. I feel I have been too emotional.	1	2	3	4	5
i. It's hard to think things through coolly and logically.	1	2	3	4	5
o. I feel as if I am no longer a whole man.	1	2	3	4	5
p. I feel like I've lost part of my manhood.	1	2	3	4	5
q. I'm not the man I used to be.	1	2	3	4	5
r. I feel that others think that I'm not the man I used to be.	1	2	3	4	5
s. I feel weak and small.	1	2	3	4	5

## Section Seven: Living With Prostate Cancer

1. How true is each of the following statements for you?

	Not at All	A Little Bit	Somewhat	Quite a Bit	Very Much
a. I am confident that my cancer is under control.	1	2	3	4	5
b. I worry that my cancer might come back.	1	2	3	4	5
c. I worry about my cancer spreading.	1	2	3	4	5
d. I feel that my cancer has given me a better outlook on life.	1	2	3	4	5
e. I worry keep my thoughts about prostate cancer to myself.	1	2	3	4	5
f. I feel that coping with cancer has made me a stronger person.	1	2	3	4	5
g. I wonder whether the treatment I got for prostate cancer really worked.	1	2	3	4	5
h. It worries me that I can't tell what is going on with my prostate cancer.	1	2	3	4	5
i. Finding the prostate cancer saved my life.	1	2	3	4	5
j. I wonder if I would have been better off with a different treatment.	1	2	3	4	5
k. I sometimes wonder whether it was really worthwhile being treated at all.	1	2	3	4	5
l. I sometimes feel the treatment I had was the wrong one for me.	1	2	3	4	5
m. I had all the information I needed when a treatment was chosen for my prostate cancer.	1	2	3	4	5

1. How true is each of the following statements for you?

	Not at All	A Little Bit	Somewhat	Quite a Bit	Very Much
n. My doctors told me the whole story about the effects of the treatments.	1	2	3	4	5
o. I wish I had chosen a more aggressive treatment for my prostate cancer.	1	2	3	4	5
p. I knew the right questions to ask my doctor.	1	2	3	4	5
q. I had enough time to make a decision about my treatment.	1	2	3	4	5
r. If I had it to do over, I would choose some other treatment.	1	2	3	4	5
s. I am satisfied with the choices I made in treating my prostate cancer.	1	2	3	4	5
t. I sometimes wish I could change my mind about the kind of treatment I chose for my prostate cancer.	1	2	3	4	5
u. People in my life don't understand what it's like to have prostate cancer.	1	2	3	4	5
v. People in my life have been very supportive since I was diagnosed with prostate cancer.	1	2	3	4	5



2. Overall, how satisfied are you with the care you have received for your prostate cancer?

Not at all	A little bit	Somewhat	Quite a bit	Very much
1	2	3	4	5

3. Overall, how satisfied are you with the way things have turned out since you found out you had prostate cancer?

Not at all	A little bit	Somewhat	Quite a bit	Very much
1	2	3	4	5

## Section Eight: General Attitudes

1. How true is each of the following statements for you?

	Not at All	A Little Bit	Somewhat	Quite a Bit	Very Much
a. When a man is feeling a little pain he should try not to let it show very much.	1	2	3	4	5
b. A man always deserves the respect of his wife and children.	1	2	3	4	5
c. It is essential for a man to have the respect and admiration of everyone who knows him.	1	2	3	4	5
d. It bothers me when a man does something that I consider feminine.	1	2	3	4	5
e. In an emergency a man should be able to take charge.	1	2	3	4	5
f. Lack of erection will always spoil sex for a man.	1	2	3	4	5
g. A man should never back down in the face of trouble.	1	2	3	4	5
h. I think a man should try to become physically tough, even if he's not big.	1	2	3	4	5
i. I admire a man who is totally sure of himself.	1	2	3	4	5
j. A man should always think everything out coolly and logically, and have rational reasons for everything he	1	2	3	4	5

1. How true is each of the following statements for you?

	Not at All	A Little Bit	Somewhat	Quite a Bit	Very Much
does.					
k. A man should never go to other people for help if he can manage things himself.	1	2	3	4	5
l. A man will lose respect if he talks about his problems.	1	2	3	4	5
m. Men are always ready for sex.	1	2	3	4	5

### Section Nine: Health Behaviors

1. How often do you...

	Never / Rarely	Sometimes	Regularly
a. Read articles or buy literature in order to learn more about ways to protect your health?	1	2	3
b. Watch or listen to programs on the TV or radio to learn more about protecting your health?	1	2	3
c. Visit web sites on the internet to learn more about your health?	1	2	3
c. Exchange information with your friends about ways to keep your health at its best?	1	2	3
d. Perform self-examinations or check over parts of your body in order to check for physical changes that might require medical attention?	1	2	3
e. Attend prostate cancer support groups?	1	2	3

2. During the past 4 weeks, how much of the time did you...

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	None of the Time
a. Think about how your body feels?	1	2	3	4	5
b. Try to figure out how your body works?	1	2	3	4	5
c. Notice changes in how your body feels?	1	2	3	4	5
d. Wonder why your body feels the way it does?	1	2	3	4	5

## Section Ten: Your General Health

The questions in this section pertain to your health in general, and how any health issues you may have affect your daily life.

1. In general, would you say your health is:

Excellent	Very Good	Good	Fair	Poor
1	2	3	4	5

The following items are about activities you might do during a typical day.

2. Does your health now limit you in these activities? If so, how much?

	Yes, Limited a Lot	Yes, Limited a Little	No, Not Limited at All
a. Moderate activities such as moving a table, pushing a vacuum cleaner, bowling or playing golf	1	2	3
b. Climbing several flights of stairs	1	2	3

3. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	Yes	No
a. Accomplished less than you would like	1	2
b. Were limited in the kind of work or other activities	1	2
c. Cut down the amount of time you spent on work or other activities	1	2
d. Had difficulty performing the work or other activities (for example, it took extra effort)	1	2

4. **During the past 4 weeks**, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	Yes	No
a. Accomplished less than you would like	1	2
b. Didn't do work or other activities as carefully as usual	1	2
c. Cut down the amount of time you spent on work or other activities	1	2

5. **During the past 4 weeks**, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Somewhat	Quite a bit	Very much
1	2	3	4	5

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one best answer that comes closest to the way you have been feeling.

6. During the past 4 weeks, how much of the time...

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
a. Have you felt calm and peaceful?	1	2	3	4	5	6
b. Did you have a lot of energy?	1	2	3	4	5	6
c. Have you felt downhearted and blue?	1	2	3	4	5	6
d. Did you feel full of pep?	1	2	3	4	5	6
e. Have you been a very nervous person?	1	2	3	4	5	6
f. Have you felt so down in the dumps nothing could cheer you up?	1	2	3	4	5	6
g. Did you feel worn out?	1	2	3	4	5	6
h. Have you been a happy person?	1	2	3	4	5	6
i. Did you ever feel tired?	1	2	3	4	5	6

7. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
1	2	3	4	5

8. Compared to one year ago, how would you rate your health in general now?

Much better now	Somewhat better now	About the same	Somewhat worse now	Much worse now
1	2	3	4	5

12. How TRUE or FALSE is each of the following statements for you?

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a. I think my health will be worse in the future than it is now.	1	2	3	4	5
b. In the future, I expect to have better health than other people I know.	1	2	3	4	5
c. I expect to have a very healthy life.	1	2	3	4	5
d. I expect my health to get worse.	1	2	3	4	5
e. My future will be unhealthy.	1	2	3	4	5
j. Good health is in my future.	1	2	3	4	5

14. During the past 4 weeks, how much have you felt...

	Not at All	A Little Bit	Somewhat	Quite a Bit	Very Much
a. My health could take a turn for the worse at any time.	1	2	3	4	5
b. I doubt that cancer will ever be a big problem for me.	1	2	3	4	5
c. I sometimes worry about dying before my time.	1	2	3	4	5
d. I worry about what my doctor will find next.	1	2	3	4	5
e. I worry that changes in my medical condition will not be detected early.	1	2	3	4	5
f. I am uneasy about the present state of my health.	1	2	3	4	5
g. It is hard to make sense of what I am told about my health.	1	2	3	4	5

15. How true has each of the following statements been for you during the past 4 weeks?

	Not at All	A Little Bit	Somewhat	Quite a Bit	Very Much
a. I keep close track of my PSA.	1	2	3	4	5
b. I live in fear that my PSA will rise.	1	2	3	4	5
c. I am confused by what PSA really means.	1	2	3	4	5
d. Knowing my PSA level is comforting to me.	1	2	3	4	5

## Section Eleven: Personal Background Information

1. Which category best describes your race / ethnic background?

White	Black / African-American	Hispanic / Latino	Asian / Pacific Islander	Aleutian, Eskimo, or American Indian	Other
1	2	3	4	5	6

2. What is your current marital status? (Circle one number.)

Married	Widowed	Separated	Divorced	Never married
1	2	3	4	5

3. How would you describe your current work or retirement situation? (Circle one number.)

Working at a paying job full or part time	Retired, not working at all	Retired, but working part or full time	Laid off or unemployed	Other
1	2	3	4	5

The following list includes events that may occur in anyone's life from time to time. Each one may have a good effect, a bad effect or no effect on a person's life. Think back over the **past 12 months** of your life.

4. Over the **past 12 months**, have any of the following events occurred in your life?

	Yes	No
a. Someone close to you had a serious illness or injury.	1	2
b. You had a financial crisis.	1	2
c. Someone close to you died.	1	2
d. You resigned or retired from work.	1	2



*Thank you for completing The Prostate Cancer Quality of Life Questionnaire.*

Have you...

- Reviewed and circled all the answers? ☐
- Signed the informed consent form on the second page? ☐

Enclose both the survey AND the informed consent form in the self-addressed stamped envelope we have provided for you and drop in any mailbox.

If you should have any questions, please call Kristen Solemina at (781) 687-3255.